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Abstract

As in other countries worldwide, adults with severe mental illness (SMI) in Brazil are disproportionately infected with HIV relative to the general population. Brazilian psychiatric facilities lack tested HIV prevention interventions. To adapt existing interventions, developed only in the U.S., we conducted targeted ethnography with adults with SMI and staff from two psychiatric institutions in Brazil. We sought to characterize individual, institutional, and interpersonal factors that may affect HIV risk behavior in this population. We conducted 350 hours of ethnographic field observations in two mental health service settings in Rio de Janeiro, and 9 focus groups ($n = 72$) and 16 key-informant interviews with patients and staff in these settings. Data comprised field notes and audiotapes of all exchanges, which were transcribed, coded, and systematically analyzed. The ethnography characterized the institutional culture and identified: 1) patients’ risk behaviors; 2) the institutional setting; 3) intervention content; and 4) intervention format and delivery strategies. Targeted ethnography also illuminated broader contextual issues for development and implementation of HIV prevention interventions for adults with SMI in Brazil, including an institutional culture that did not systematically address patients’ sexual behavior, sexual health, or HIV sexual risk, yet strongly impacted the structure of patients’ sexual networks. Further, ethnography identified the Brazilian concept of “social responsibility” as important to prevention work with psychiatric patients. Targeted ethnography with adults with SMI and institutional staff

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provided information critical to the adaptation of tested U.S. HIV prevention interventions from the US for Brazilians with SMI.

Keywords

Targeted Ethnography; HIV Prevention; HIV Prevention Intervention; Cultural Adaptation; Severe Mental Illness; Brazil; psychiatric institutions

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INTRODUCTION

Worldwide, where rates of HIV infection have been established, adults with severe mental illness (SMI) have sharply elevated rates of HIV infection relative to the general population in the same geographic region (McKinnon, Cournos, Herman, & Le Melle, 2005) and appear to engage in higher rates of some risk behaviors (Carey, Carey, & Kalichman, 1997; Chandra, Carey, Carey, Rao, Jairam, & Thomas, 2003; Meade & Sikkema, 2005). Prevalent among people diagnosed with SMI (i.e., schizophrenia, schizoaffective disorder, bipolar disorder, and major depression with psychotic features) are HIV risk behaviors such as having unprotected sex, multiple partners, high-risk partners; trading sex for money, drugs, or shelter; and using substances before sex. Because people with SMI may belong to any number of overlapping risk networks due to high rates of comorbid substance abuse, poverty, and marginalized social status, they need HIV prevention interventions that address an array of complex conditions through learning techniques known to be effective with people with SMI.

Brazil is no exception. Although the epidemic among adults with SMI in Brazil is not well described, a study in Belo Horizonte, Brazil, found the HIV infection rate among adults with SMI to be over five times higher than the prevalence of the local general population (1.6% vs. 0.3%) (Almeida & Pedroso, 2004; Ministry of Health, 2005). A risk behavior study among patients with SMI in Rio de Janeiro, found considerable sexual risk-taking in the previous year: 63% were sexually active; of those, 72% did not use condoms regularly and 49% never used condoms (Oliveira, 1997). New seroprevalence and risk behavior studies are underway throughout Brazil (M. Guimarães, personal communication, January 12, 2006).

The Brazilian National Government has identified adults with SMI as a group vulnerable to HIV infection (Ministry of Health, 1999). However, specialized prevention programs that have emerged from Brazil's National HIV Program have targeted men who have sex with men, commercial sex workers, and injection drug users, but not people with SMI. Without an efficacious HIV prevention intervention tailored to their specialized needs, adults with SMI in Brazil will continue to be vulnerable to HIV infection yet unprepared to protect themselves and others from infection.

Several existing U.S. interventions have demonstrated efficacy at helping psychiatric patients reduce their HIV risk behaviors (Kalichman, Sikkema, Kelly, & Bulto, 1995; Kelly, McAuliffe, Sikkema, Murphy, Somlai, Mulry, et al., 1997; Susser, Valencia, Berkman, Sohler, Conover, Torres, et al., 1998; Weinhardt, Carey, Carey, & Verdecias, 1998; Otto-Salaj, Kelly, Stevenson, Hoffmann, & Kalichman, 2001; Carey, Carey, Maisto, Gordon, Schroder, & Vanable, 2004). Because each of these interventions targeted diagnostically different patient groups and, despite similar theoretical foundations, their implementation differed in terms of gender composition, number of sessions, duration, content, and message delivery strategies, there was no single tested HIV prevention intervention that we could adapt for Brazilian SMI. Therefore, we conducted an NIMH-funded collaboration study between U.S. and Brazilian researchers and mental health care providers to build upon the tested interventions. Our goal was to adapt, refine, and pilot a provider-delivered HIV prevention intervention for adults with SMI in outpatient psychiatric settings in Rio de Janeiro. The process for adapting the existing efficacious interventions for psychiatric patients in Brazil has been described in detail elsewhere (Wainberg, McKinnon, Mattos, Pinto, Gruber Mann, Oliveira, et al., in press). As a critical part of the adaptation process, we conducted targeted ethnography to elucidate the local HIV sexual risk behaviors, the factors influencing HIV risk, and the contexts in which these occur among people with SMI. This paper describes the procedures and findings of the targeted ethnography phase of the study.

Ethnographic methods have broad application for HIV prevention research, generating a richer understanding of sexuality, sexual identity, and sexual (risk) behaviors (Parker & Ehrhardt, 2001). Ethnography provides a detailed and in-depth account of the local context and social ecology in which an intervention is to be implemented, helping to understand prevalent norms, attitudes, and strategies salient to HIV prevention intervention (Hopson, Peterson, & Lucas, 2001; Sivaram, Srikrishnan, Latkin, Johnson, Go, Bentley, et al., 2004). Without attention to the new cultural setting, adapted interventions may remain faithful to the theoretical or empirical underpinnings on which they were originally based, but will lack relevance, sustainability, and acceptability for the new target population (Bauman, Stein, & Ireys, 1991; Castro, Barrera, & Martinez, 2004). Ethnographic methods have been used to evaluate or adapt HIV prevention interventions in other populations and settings (e.g. Hopson, et al., 2001; Sivaram, et al., 2004).

The inclusion of adults with SMI in the adaptation or development process of an HIV prevention intervention has not been described in the literature until quite recently (Gordon, Carey, Carey, Maisto, & Weinhardt, 1999; Kloos, Gross, Meese, Meade, Doughty, & Sikkema, 2005). None of these studies incorporated the experiences of both patients and staff.

In the current study, we used targeted ethnographic methods (field observations, focus groups, and key-informant interviews) with the target population (adults with SMI) and with outpatient staff to inform the cultural translation of the existing U.S. intervention models. Our ultimate goal was to increase the relevance of the intervention content and the likelihood of its acceptability to potential users of the intervention. We sought to: 1) characterize from both patient and staff perspectives the predominant HIV risk behaviors (sexual and drug-use) of patients; 2) illuminate the context in which these risk behaviors take place (individual, group, social, institutional, geographic); and 3) elicit patient and staff priorities regarding HIV prevention intervention content, format, and delivery strategies.

METHODS

Because the theoretical models of the efficacious U.S. prevention interventions had not been tested in Brazil, we used methods from grounded theory (Strauss & Glaser, 1965) to collect and interpret data. Investigators generated conceptual categories from evidence; then the evidence from which the category emerged was used to illustrate the concept. In grounded theory, the purpose is not to produce evidence that is accurate beyond a doubt, but to derive concepts which are relevant theoretical abstractions about what is going on. We obtained data from three sources: 1) field observations; 2) focus groups; and 3) interviews with key informants. These were collected, coded, and analyzed simultaneously; our initial coding decisions were not based on any specific preconceived theoretical framework of HIV risk behavior.

Setting and Participants

The targeted ethnography was carried out between January 2003 and April of 2004 in two adjacent psychiatric inpatient/outpatient institutions located in the center of Rio de Janeiro. Both institutions have been operating for more than 60 years; both integrate training, research, and clinical services (day treatment, outpatient, two inpatient units). The State of Rio de Janeiro has the highest AIDS incidence in Brazil (31.6 per 100,000 inhabitants) and its capital city has 89.9% of AIDS cases in the state (Ministry of Health, 2005). The targeted ethnographic work was conducted in two phases: 1) field observations of both psychiatric centers and their surrounding areas; and 2) focus groups (n = 72; SMI = 45, staff = 27) and key-informant interviews (n = 16; SMI = 10, staff = 6) with staff in both centers and with sexually active patients receiving care at one of the centers (patients at the other center were not involved so that they could participate in future pilot testing of the produced intervention). Participants in the focus groups and key-informant interviews included sexually active day-hospital patients and outpatients, and different levels of clinical and administrative staff (e.g., professional, paraprofessional, housekeeping, etc.). Field observation participants also included inpatients[1] (being sexually active was not required for field observation participation). Participants were not compensated in accordance with Brazilian research regulations. The institutional review boards of all institutions involved in the study approved all study procedures and consent forms.

Field observations

Two research assistants who were licensed clinical psychologists (one female and one male) conducted and recorded field observations in several areas of both hospitals (e.g., day-hospital, ambulatory clinic, inpatient wards, and several physical spaces where both patients and staff gather or circulate regularly – cafeteria, garden, parking lot, entrances, restrooms). Field observations did not require obtaining written informed consent. One hundred and eleven systematic observations were conducted at regularly scheduled times and intervals (weekdays, mornings, afternoons, and evenings) over a total of 350 hours, between January and April 2003. Field notes were produced after each field observations with emphasis on documenting verbatim any conversations ‘observed’ or ‘involved in.’ Saturation (i.e., a sufficient number of field observations) was reached for specific time periods of the institutions’ operating hours and on specific days in accordance with principals of grounded theory in qualitative research (Strauss & Corbin, 1994). Field notes were used to determine topics for further exploration in focus groups.

Focus Groups

Patients who were ages 18 to 65, sexually active in the last three months, diagnosed with SMI, and not suicidal were recruited using a combination of active and passive techniques designed to notify individuals who might not volunteer for a focus groups on their own (Morgan, 1990). Flyers advertising the study were placed in clinic waiting areas; clinic providers informed patients of the study; and research assistants approached patients in the waiting room during randomly selected clinic sessions. To recruit staff, invitation letters describing the nature and scope of participation in the focus groups were distributed in both institutions.

Patient capacity to give written informed consent was determined by a member of the treatment team and then confirmed by a psychiatrist member of the research team; this procedure was also use for the key-informant interviews. As part of the informed consent process, patients and staff were told that researchers were interested in talking to them in a group setting or individually (i.e., focus groups or key-informant interviews) about issues relating to sexuality and HIV prevention. Investigators explained to interested patients and staff that participation was voluntary and was in no way related to receipt of care at the clinic or job security at the hospitals, respectively. Because of the sexual content of the inquiry, participants were assured that information obtained could not be reported to their providers or employers.[2] Those interested in participating provided written informed consent.

A total of nine focus groups were carried out, six with patients and three with staff; each lasted ninety minutes. Of the six conducted with patients (*n* = 45; F = 26/M = 19; ages ranging from 24–55 years), two were with women only, two were with men only, and two were with male and females in the same group. Demographic and diagnostic data were not collected due to local IRB guidelines restricting elicitation of identifying characteristics. However, we estimated demographic and clinical characteristics in aggregate drawing from reports from clinicians who determined capacity to consent, checklists completed during group discussions, and transcribed materials. Using Brazilian ethnic categories, about half of the participants were described as white, four as ‘negros,’ and the rest as multiracial. Approximately two-thirds of participants per group were single; the rest were either married/in a long-term relationship or divorced, widowed or separated. About half of the participants had a diagnosis of schizophrenia; the rest carried diagnoses of bipolar disorder, schizoaffective disorder, or major depressive disorder with psychotic features. Some participants had comorbid substance use disorders. About half of the participants had completed primary school and the rest had completed secondary school. These characteristics are typical of the overall population of patients served in these psychiatric settings. Staff (*n* = 27; F = 17/M = 10; ages ranging from 28–67 years) from both institutions participated in the remaining focus groups, one each for the following staff groups: managerial (directors, *n* = 5; F=2/M=3), clinical (psychiatrists, nurses, psychologists, *n* = 13; F=10/M=3), and auxiliary staff (nursing assistants, maintenance staff, *n* = 9; F=4/M=5).

The focus groups were led by two moderators (doctoral-level in social sciences or licensed psychologists) experienced in conducting focus groups and specifically trained by the research team. focus groups ranged in size from 5 to 13 participants each; questions were developed by the U.S.-Brazil multidisciplinary study team, prompted by pertinent themes from the field observation notes that required further elaboration. The focus groups were conducted using semi-structured questionnaires; Table 1 presents the scripts used in the focus groups with patients and in those with staff. All focus groups were audiotaped.

The focus groups aimed to elicit important aspects of the content and implementation (format, delivery strategies) of the intervention. Their goal was to gather the underlying representations, ideas, and prejudices of the patients and staff as well as their unique descriptions of the context in which risk behaviors took place and in which the intervention would be implemented. Because we were adapting U.S. interventions to a new culture, all focus groups assessed from the perspective of patients or staff: 1) behaviors, experiences, meanings, values, attitudes, and norms related to the key HIV risk behaviors that were uncovered; 2) preferences for intervention content, activities, timing, location, and gender composition; and 3) relevance of, need for, and comfort with an HIV prevention intervention.

Key Informant Interviews

Key informants were identified and recruited from the focus groups or the field observations; these informants were ‘specialists’ (Agar, 1996) on the subject matter (i.e., they participated in meaningful ways, reported important risk behavior incidents, were identified by other participants as knowledgeable). Sixteen key-informant interviews were conducted (all were audiotaped), ten of them with patients (6 men and 4 women) and six with staff (2 from each focus group).

After informed consents were signed, the participants were scheduled for an interview with an investigator (doctoral-level in social sciences or a licensed psychologist) experienced in conducting key-informant interviews. The semi-structured interviews focused on issues that emanated from the ethnographic field notes and focus groups that required further understanding; Table 2 shows the script of questions used. All key-informant interviews were audiotaped.

Data Analysis

The use of multiple sources of data, or triangulation, enhances the validity of data obtained from any single source (Morgan, 1990). Therefore, field notes and verbatim transcripts of the audiotaped focus groups and key-informant interviews were coded in the same way and analyzed through constant comparative analysis: 1) comparing incidents applicable to each category; and 2) integrating categories and their properties (Strauss & Glaser, 1965). Three research assistants initially coded separately all notes and transcripts. Each specific mention of sex, HIV prevention, and related terms was coded. The three raters worked collaboratively to develop a taxonomy of the initial themes (e.g., reasons for not using condoms) that emerged.

After this initial coding, the three raters clarified and reached consensus about the coding scheme. As themes were identified, the transcripts were re-coded by each rater working independently to document evidence that supported or refined the themes, to examine other mentions of these themes, or to identify other themes. Specific quotations within each category were then analyzed to identify similarities or differences to determine trends that might tie them together. The coders then applied this final code list to the transcripts, first working independently and then comparing codes in order to achieve consensus. In cases where there was disagreement among the raters, only themes about which two or more coders agreed were included in the final analysis. Decision trails were documented to assure that interpretations were supported by the data. Four investigators supervised the coding and re-coding at different steps of this process to verify that findings were grounded in the data. Six Portuguese-speaking team members in both the U.S. and Brazil reviewed emerging findings for validation. The *ATLAS.ti* program, qualitative software, was used to code within the transcribed documents and explore qualitative findings (www.atlasti.com).

RESULTS

To determine modifications to existing efficacious HIV prevention interventions, our ethnographic study focused on four discrete categories: 1) patients’ risk behaviors; 2) the institutional setting; 3) intervention content; and 4) intervention format and delivery strategies. The former two encompass the specifics of the local setting, target population, and need for an HIV prevention intervention. The latter two represent specific recommendations to inform adaptation of previously tested HIV prevention interventions.

Taken together, findings show a complex picture of the sexual lives of psychiatric patients and of how their risk for or protection from HIV infection may stem from a combination of individual, interpersonal, and institutional factors. To illustrate those findings, we present quotations taken from the ethnographic field observations (FO), focus groups (FG), and key-informant interviews (KII) that highlight intervention-relevant findings.

Patients’ HIV risk behaviors

HIV risk behaviors uncovered in this study were almost exclusively sexual rather than related to substance use practices.

Patients are sexual—Brazilian psychiatric patients reported engaging in sexual relationships that were sources of sexual and emotional fulfillment.

> Sexuality for me is … to feel something for someone. A deeper feeling, right? To let someone come closer to me and then get a kiss, a hug and then a caress, right? It’s not just [sex] … coming closer, you get to know the person first and then one finds out about each other.
>
> [KII11, female patient]

> … there's a difference between sex and love. Why? Sex, just sexual practice, you turn backwards and it's done. Love is different. When we feel love inside us, as human beings … we do not use.. how can I say? Sex as sex, for me … It's to use men and women as a sexual object. When it comes to love, it's an attraction that comes from the body, the soul and the heart. If you don't have heart, you don't have love, right?
>
> [FG15, patient in all male group]

Treatment settings are central to patients' sexual lives—Numerous field observations notes reported patient couples holding hands. The clinic/hospital grounds were an important place in patients' social lives, and romantic and/or sexual encounters took place within the confines of the psychiatric clinics they regularly attended.

> I think it is, undoubtedly, easier for [patients] to… meet other partners here. Partially because this is the place they often come to. Cause where do we end up meeting boyfriends? Where we usually are, whether at the workplace, or in college, or in our group of friends.
>
> [KII3, female staff]
>
> She (a female patient) said that the only good thing about (the hospital) was to have sex in the wards during the night.
>
> [FO2, female patient]

Patients experience stigma related to mental illness that affects their sexual lives—Patients expressed a feeling of being sexually different from others and of being treated differently by others sexually because of their mental illness.

> I have to be chosen, I'm ill and I can't choose [my sexual partners].
>
> [FO14, male patient]
>
> I was getting out of the hospital, then there was this guy in the bus and he says, "Look how cute she is, it's a pity that she's nuts." This is the stigma we deal with.
>
> [FG24, female patient in a mixed-gender group]

Patients are aware of and have knowledge about HIV—Some patients had basic knowledge about transmission and risk behaviors and reported having learned from governmental public health campaigns, outpatient drop-in groups about sexual health, or because they had been acquainted with patients infected with the virus. However, inaccurate knowledge and misperceptions also were present.

> …[using condoms] is much more dangerous, the condom might break.
>
> [KII11, female patient]

Sexually active psychiatric patients are sexually risky—Even informants knowledgeable about HIV transmission and risk behaviors reported not practicing safer sex: they infrequently used condoms, dental dams, or other methods of preventing HIV transmission (i.e., non-penetrative sex).

> They (patients) do know about it (prevention); there are people here who are informed about it as well as people who aren't, the same as with the general population, but in general what makes them not protect themselves is more the search for pleasure …. They do not bother. The family sometimes brings them condoms, but more often than not they don't even use them.

> [FO22, female staff]
>
> It [sex in the inpatient units] happens without any control and it is totally unprotected, but most of the time, it is consensual.
>
> [FO2, male patient]
>
> …[she] had sex with me with no condom …man, she knows I'm HIV positive…
>
> [FO22, male patient]

Patients' attitudes about condoms influence condom use—Patients offered diverse reasons for not using condoms, including dislike of condoms, difficulty using them in the heat of the moment (with some regret), feeling ashamed to use them or a lack of assertiveness to use them, fearing the partner would feel insulted, relying on luck or past experiences to argue for an equally fortunate future, or assumptions about HIV status based on the appearance of casual or romantic partners.

> You'll always have to live with that…stupid annoying condom…it's a strange element. It takes away half of the pleasure…
>
> [GF15, patient in all male group]
>
> Oh! We think about it later, but right at the moment it's just the desire to have sex, and then the regret. After you come, there's the regret …
>
> [KII11. female patient]
>
> …when I use a condom with a woman, I think I'll…be hurting her, thinking that she's sick …
>
> [KII6, male patient]
>
> But if I have to have sex with a woman outside the hospital, I won't use the condom. I don't think that it is risky… I would choose very well the partner with whom I would have (sex)…
>
> [KII9, male patient]
>
> When I use a condom with a woman, like, for example, if I get a condom to use it with a woman (I think that), I'll be like being aggressive, thinking that she's sick…
>
> [KII7, male patient]

Other patients reported 'concerns' about condoms and their efficacy to prevent transmission, stemming, according to staff and patients, from the position and influence of several Brazilian churches which have taken public positions that condoms are not an effective prevention method. It was not uncommon for patients to 'believe' in magical or religious protective mechanisms against getting HIV infection.

> I've already met people who got AIDS using condoms that break… …I think that He [God] is aware of everything that He'll do to me.
>
> [KII6, male patient]

The institutional setting

Policies proscribing sexual activity within the hospital are not consistently enforced—Staff confirmed that both mental health settings had policies proscribing sexual activity within the hospital. However, how to apply this policy was unclear, staff did not always know how to proceed, and they expressed their confusion.

> I heard many times, from nurses, nursing assistants and other professionals describing how difficult it was for them and asking me ‘what should we do, if we catch them? Separate them, right?’ It was difficult for them to deal with that. I mean, they knew it was forbidden, of course, but at the moment when things were happening, they didn’t know what to do. To my knowledge, there’s never been a specific training, but only a conversation after some incident.
>
> [GF10, female staff]

Patients expressed similar confusion about and relayed instances in which staff did not enact the ‘rules.’

> He [a patient] said that he had taken a girl to his room and that they were having sex under the sheets when a male nurse passed by and looked into the room (…) The nurse came closer and lifted the sheets (…) and caught them in the act (…) the nurse looked with indifference, and then he just lowered the sheet and went away.
>
> [FO16, male patient]

Staff view patients’ sexuality as a function of their psychiatric condition—Some staff viewed their patients’ sexual activity and lack of consistent condom use in terms of pathology as opposed to normative behavior.

> Sometimes I think that psychiatric patients, depending on our attitudes, also lack the capacity to be reasonable, their personality, I don’t know if we can call it that, but they suffer from some symptoms, you know?
>
> [GF9, male staff]
>
> One thing is when you’re healthy, nobody takes advantage of you and you have your judgment preserved, and as we say, we do not buy our mental ability, right? And then you can decide whether you wanna use condom or not. Another thing is when you have that part aroused, what happens very, very often with psychiatric patients. Some get down due to medication, others get excited, and this might lead to things, let’s say, to thoughtless acts.
>
> [KII13, female staff]

Guidelines and training for dealing with HIV risk-related behaviors are not in place—Staff often were not aware of institutional policies or protocols regarding HIV prevention and were left to do what they considered appropriate without benefit of institutional guidance or training to address patients’ sexual activity. One staff member recounted her frustration during an interaction with a patient who was likely about to engage in HIV risk.

> *The patient tells me ‘Doctor, I’m off to the prostitutes …’ So I tell him ‘Ok, but you know that you’ve got to use …’ But he interrupts saying ‘Yeah.’ So, I leave it at: Ok.* [Explaining to the interviewer] *Got it? Like, I’m gonna tell him ‘No, no.’ Right? No way. I ain’t gonna do that, you know?*
>
> [KII4, female staff]

The lack of institutionally-provided training about patients’ sexual expression opened the door for staff’s idiosyncratic strategies to manage it.

> It is not lack of information, I think that professionals have information; I think that what they lack is skills, tactfulness, and openness.
>
> [KII5, male staff]

Staff's attitudes about condoms influence condom availability—

Despite strong human rights protections of sexual freedom in Brazil, condoms are not universally provided in psychiatric treatment settings. Some staff expressed concerns over the possibility of making condoms available to patients, believing that doing so would encourage sexual activity. The idea that offering condoms to patients could help make condoms more familiar, promote healthy sexuality, and make sex safer also was not expressed by staff.

> If you give condoms in the ward in a psychiatric hospital like ours and put the guy in there, in the patio (…) so, 'give me a condom', cause it's allowed? What's he gonna do with the condom? Is he gonna play with it or is he gonna have sex with someone?
>
> [FG8, female staff]

Content-specific issues to address in targeted prevention interventions for this population

Sex is the priority for HIV prevention in this population, but substance use can trigger unsafe sex—

In addition to improving communication and safer sex negotiation skills, as well as challenging assumptions about their partners' health and attitudes toward condoms, addressing substance use related to sex was described as necessary for decreasing sexual risk behaviors. Both staff and patients described that alcohol and other drugs were present in the lives of patients inside and outside of the institution and could trigger risky sex.

> He is schizophrenic, he drinks sometimes. And when he leaves [the hospital], boy, [sexual] risk behavior, like, is much bigger. Much bigger indeed. Once he stayed out in the streets drinking a lot, he was missing during the weekend and after three months, we even had him tested…
>
> [KII4, female staff]

Families are involved in all aspects of patients' lives, including their sexuality and its expression—

Another key finding related to content was the important role of family in the lives of psychiatric patients. Many patients live with relatives, some of whom keep close watch on the psychiatric care their loved ones receive. Staff and patients in the groups agreed that in any HIV prevention intervention, families could both facilitate and impede its success. Patients and staff brainstormed about how to incorporate relatives into a prevention intervention; not all ideas were applicable to all patients. However, they all agreed that patients required tools to communicate assertively with their relatives about sexual matters to allow them some independence, a healthier sexual life, or to be able to define what to disclose to relatives about their sexual lives.

> We have many young adult patients whose relatives do anything they can to prevent their children from having sex, and I mean anything!
>
> [FG31, female staff]

Patients feel a strong sense of social responsibility which should be reinforced in an HIV prevention intervention—

In addition to protecting themselves, patients also expressed their wish and need to learn more about HIV prevention so that they could share that knowledge with relatives, friends, and fellow patients; they valued their community membership and expressed their sense of "social responsibility."

> It could be of great utility, I could even pass what I will learn to others.
>
> [FO4, female patient]

Format and delivery strategies required when targeting prevention interventions to this population

Patients and staff were thoughtful about how they would like to see an HIV prevention intervention carried out in their treatment settings, and their opinions were quite similar.

Patients are comfortable discussing sex—Throughout all phases of the ethnography, it was evident that psychiatric patients felt comfortable talking about sex. The ethnographic observers found no reservation among patients when the goals of the study were presented to them; quite the opposite, the ethnographers were sought out by the patients, a phenomenon documented in innumerable field notes.

> After I responded what type of research we are conducting, several patients asked me to be their psychologist so they could talk about sex with a mental health professional.
>
> [FO16, female observer field note]

Group discussions and activities are common in treatment settings—Within the focus groups, patients felt comfortable talking about sex and risk behaviors and discussing sensitive issues; group activities are common to them in their treatment programs. The idea of a closed-group format (non-changing membership) was expressed as being desirable within all focus groups with patients and confirmed during the key-informant interviews. Staff expressed similar preferences and their comfort with a program anywhere from six to ten weekly sessions.

> Like the ones [focus groups] you're having, group discussions, so that people's doubts are clarified.
>
> [KII6, with female patient]
>
> Well, the first thing that comes to my mind is that this type of work may be very rich if it is done with small groups.
>
> [KII5, with male staff]

Structure is necessary for cohesive group learning and interactive activities—Patients suggested, and staff concurred, that the intervention should be structured as a course with interactive lessons and a certificate upon "graduation." Patients and staff also stressed that the intervention needed to use interactive exercises to motivate participants and to allow for 'hands-on' learning of information and prevention skills. There were no doubts among participants and staff that Brazilian music, as well as activities with body movement, would need to be woven into the intervention.

> I think a theatre play should be created. To teach how to use the female and the male condom.
>
> [KII11, female patient]

Mixed-gender group membership is important for learning, and facilitators should be a co-educational pair, experienced and well trained—When patients and staff were asked about intervention group membership and facilitators, consensus was clear about having mixed-gender groups run by two facilitators, one female and one male. Staff expressed the strong preference for facilitators to be well trained or to have experience working with adults with SMI to manage therapeutically any problems that might arise during the intervention sessions.

> In my opinion men and women should be together.

> [KII1, female staff]
>
> There are two perspectives, the two are different. It brings more discussion. Yet, it would be helpful if there are two facilitators, one of each gender.
>
> [KII14, male staff]
>
> Well, the coordinators, the nurses, psychologist [would be in charge of these groups] … as long as they are well trained to do this.
>
> [KII1, female staff]

Patients want to be empowered to educate each other—Psychiatric patients were willing to be HIV peer-educators and expressed relief at the possibility of not having always to depend on their mental health care providers for information and support. Staff felt that their patients could learn to educate other patients and function as peer-educators.

> Why do we need to depend on the professionals to discuss sexuality among other things? Why can't we get together either in a small or in a big group, I don't know, in the room next door (in the hospital)?… let's do it, guys, we can do it. I do think it's great that there's someone we can talk to about these things, but let's not depend on others, right?
>
> [FO21, male patient]

DISCUSSION

The targeted ethnographic methods of observation, focus groups, and in-depth interviews with psychiatric patients and staff enabled us to identify cultural aspects related to HIV risk and prevention (e.g., the sense of "social responsibility", the potential role of Brazilian music and body movements, the influence of several Brazilian churches against the use of condoms, the importance of the family in the patient's sexuality) that are specific, possibly unique, to people with SMI in Brazil. Ethnographic methods also allowed us to understand how interventions for people with SMI that were developed elsewhere could serve as the foundation in Brazil for clarifying knowledge, addressing misconceptions, increasing motivation for safer sex behaviors, and improving communication and negotiation skills with this population. Overall, we found that patients with SMI who attended the two psychiatric treatment programs were sexually active and often expressed that they found pleasure and fulfillment in these relationships. These findings are in contrast to some perceptions that sexual desire in people with SMI is driven by pathology rather than by the normal human need for emotional and/or physical connection and gratification.

Patients used condoms inconsistently, sometimes with known HIV-positive partners, even when they had accurate knowledge of HIV risks and related information. These findings are consistent with studies of adults with SMI outside Brazil (McKinnon, et al., 2005) that find a gap between knowledge of HIV prevention techniques (e.g., condom use) and the actual practice of those techniques (e.g., inconsistent use). As in those studies, addressing this gap, as well as any misinformation patients possess, would be an important part of any HIV intervention for SMI in Brazil.

The ethnography also uncovered the need to address sexual issues related to mental illness stigma, particularly the notion of being unable to choose one's sexual partner, and the impact this may have on unsafe sexual practices. The sense of being "different" may contribute to increased feelings of self-depreciation among adults with SMI (Wright, Gronfein, & Owens, 2000), which may in turn decrease their ability to negotiate and insist on condom use. The effects of mental illness stigma on sexual risk behavior, a relatively unexplored area of HIV risk among people with SMI, need to be studied further, and not only in Brazil. Identifying effects of mental illness stigma could help to address critical social determinants of patients' HIV risk behaviors.

In all ethnographic approaches we used, patients with SMI demonstrated comfort in talking about sex and appeared to welcome the opportunity to discuss related sensitive topics in groups comprised of both men and women. Moreover, they expressed the wish to learn about HIV prevention skills and reported that they would participate in an intervention if it were offered in their treatment setting and, further, would enjoy the opportunity to act as educators to other patients as a way of enacting their strong sense of "social responsibility." Both staff and patients suggested that a provider-led, short-term structured small-group intervention was the best approach for incorporating HIV prevention into the routine of the clinics. Both groups expressed the need for interventions that incorporate local needs, contextual aspects of risk and protection, and prevention messages that have a Brazilian "flavor" (Wainberg, et al., in press).

Finally, the patients were receiving care for their mental illness in an institutional culture that did not systematically address their sexual behavior, sexual health, or HIV sexual risk. Yet, as in the US (Perry & Wright, 2006), the institutions strongly impacted patients' sexual networks. Staff were aware of risky behavior occurring between patients but reported feeling ill-equipped to mount prevention efforts within their institutions and help their patients move toward healthier sexual lives.

To overcome these limitations in the psychiatric institution's ability to contribute to the HIV-related public health initiatives going on throughout Brazil, it will not be sufficient to intervene only with patients. Increasing staff comfort and skills in addressing patient sexuality and protective behaviors is needed. Ideally, institution-wide implementation of HIV prevention training for staff as well as of an efficacious HIV prevention intervention for patients would become policy.

Findings from this targeted ethnographic study were used by U.S. and Brazil investigators and 20 local mental health care providers to guide the adaptation of HIV prevention interventions already tested with adults with SMI in the U.S. The resulting intervention, PRISSMA (*Projeto Interdisciplinar em Sexualidade, Saúde Mental e Aids* – Interdisciplinary Project on Sexuality, Mental Health and AIDS), will undergo a randomized controlled trial to test its efficacy to reduce HIV sexual risk behavior among Brazilian adults with SMI in outpatient settings. Instead of constructing an intervention from scratch, this process allowed investigators and clinicians to identify collaboratively how to synthesize tested prevention components with the local context and social ecology. In this way, ethnographic methods have provided critical information for the development of an intervention that is targeted to the specific needs of this specific population.

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Table 1

Scripts of the focus groups

Patient Focus Group Script	Staff Focus Group Script
1 What is sexuality? **2** How do you view the sexuality of people who use psychiatric services? **3** How do you see your own sexuality? **4** Where, with whom and when do you talk about this? **5** How is this discussed in the psychiatric institute? Why? **6** Do you think it is important to talk about sexuality with people who use mental health services? Why? **7** What does sexuality have to do with HIV and STI prevention? *Probe for*: HIV and AIDS knowledge; Risk behaviors –knowledge and feelings about it; Safer sex; Alcohol and drugs as triggers for sex and unsafe sex; Exchange sex (e.g., money, alcohol, drugs, cigarettes) and risk; Coerced sex; Psychiatric medication and sex; Stigma – mental illness and HIV **8** Would you want to talk with experts about these topics? Why? **9** What would be the ideal way? **a.** Groups or individually? **b.** Women and men together or separately? **c.** Gender of the facilitator or expertise? **d.** General discussion or structured activities? **e.** What content and activities would be important for you to cover? **f.** What time frame? Frequency, how long, ongoing? **g.** Where? **h.** What could be a control intervention? **10** How would you feel participating in the development of this intervention? **11** How did you feel about today’s group? Anything that you would like to change?	**1** Do you find it important to talk with people who use psychiatric services about sexuality? Why? *Probe for*: Language (labels, stereotypes); values and representations; sexual repression; medications and sexual function; pregnancy, STIs and HIV; alcohol and drugs; prevention (methods, knowledge) and risk; stigma **2** How do the institute’s personnel deal with this in the clinics or day-hospital? Do you talk with patients about sexuality and related topics? **3** How are HIV/STIs/AIDS and mental illness related? How are these currently addressed within your institution? *Probe for*: Prevention issues/intervention offered; treatment/medications/living with HIV; condom availability and free distribution within clinics and day-hospital **4** What are the aspects that you consider important to create an ideal intervention? **a.** Same list as in patient question 9 **5** Same as patient question 10 **6** Same as patient question 11

Table 2

Script of the key informant interviews.

Patient Interview Script	**Staff Interview Script**
1 What is sexuality for you? **2** Any differences between male and female sexuality? **3** Can you tell us about your emotional relationships and sexual relationships? **4** Do you have any relationships with people who are not receiving psychiatric care? Where and with whom do you look for sex in and out of the institution? **5** After you started your psychiatric treatment, anything changed in your life – sexually or romantically? **6** What about condoms? *Probe for*: use, negotiation. **7** What have you heard about HIV/AIDS? Do you feel that HIV/AIDS has anything to do with you? (Perception of personal risk) **8** What do you think about homosexuality? **9** What type of activity would be interesting to do to help people in psychiatric care to prevent HIV/STIs/AIDS? **a.** Type of activity **b.** With whom? (Other patients, staff, your own doctor, other providers) **c.** Genders separate or together? **d.** What type of group (dynamics of the group) **e.** Where and when? **10** Do you think that your family should be involved in this type of work? How? **11** Let's talk about alcohol use – both within and outside the hospital. Is it connected to sexual activity? And risk? **12** And drugs? Is drug use connected to sex? To risk? **13** Let's talk about religion and sexuality. Do you think that we need to include this in the intervention? How?	**1** What is sexuality for you? How do you see the sexuality of people who receive psychiatric services? **2** See patient question 2 **3** What do you think about people who receive psychiatric care and their: **a.** Emotional relationships **b.** Sexual lives **c.** Relationships (sexual and affective) with people who are not receiving psychiatric care **4** What is their perception of their own HIV risk behavior? **5** Same as patient question 6 **6** How does the issue of sex, STIs and HIV/AIDS is present in your day-to-day work in the institution? *Probe for*: any activity or intervention the interviewee has used to address prevention **7** Same as patient question 9 **8** Do you think that the patients' family should be involved in any way in this type of work? How? **9** Same as patient question 11 **10** Same as patient question 12 **11** Same as patient question 13

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[1] Inpatients participated only in the ethnographic field observations when observations where conducted on the inpatient units and researchers were approached by those patients.

[2] The approved informed consent form did explain that researchers would contact patients' treatment team in cases of any active danger to self or others, as per research standards.